Understanding Frames: A qualitative exploration of standing frame use for young people with cerebral palsy in educational settings

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Declarations
The authors declare that the work submitted is their own and that copyright has not been breached in seeking its publication.

Running foot: Understanding Frames: Educational settings

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Abstract

Background

Consensus opinion supports standing frame use as part of postural management for non-ambulant young people with cerebral palsy (CP). Most young people with CP in the UK who use standing frames, use them at nursery or school, rather than at home. In this paper we report professionals' and parents' experiences and views of standing frame use specifically in educational settings. This research was conducted as part of a large mixed methods study to determine the acceptability and inform the design of a future trial of standing frames.

Methods

Qualitative methods were used: focus groups with educational professionals, parents, and clinicians (paediatricians, physiotherapists, and occupational therapists) were convened. Data was analysed thematically using Framework analysis.

Results

Five focus groups were conducted. The overarching theme "flexibility" encompassed four subordinate themes: (i) '*balancing education and therapy',* which described the way education professionals had to juggle different priorities from health professionals within a multi-disciplinary team; (ii) '*young people's autonomy'* which highlighted participants' belief that standing frame use should be centred on the individual young person and their needs; (iii) *'working within logistical boundaries',* which demonstrated that "ideal" standing frame use was not always possible due to logistical issues (e.g., staffing, standing frame availability); and (iv) *'competence and confidence'* which highlighted that educational professionals felt that they lacked the training to confidently position young people in their standing frame.

Conclusions

This paper highlights the complexity of standing frame use in the educational setting. If a standing frame programme is prescribed to be delivered in an educational setting, strong

multi-disciplinary and inter-agency communication is essential to balance therapy versus education. Training is required to ensure staff are competent in using the standing frame with the young person understanding their individual requirements. A flexible approach – inclusive of the young person's needs, logistical demands, and resource – is necessary.

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Cerebral palsy (CP) affects one in 400 children and young people. CP is associated with spasticity and secondary musculoskeletal complications. Postural management, including standing frame use, is recommended (Gericke, 2006) and widely used in clinical practice for young people with CP who are predominately non-ambulant (i.e. Gross Motor Function Classification System [GMFCS] III-V), despite the lack of an established evidence base on the efficacy, effectiveness and cost-effectiveness of this type of therapeutic intervention (Goodwin et al 2018a).

A standing frame has a rigid frame with a wide base. A child is positioned in the standing frame with variable support that may enable movement of the head, upper body, and upper limbs, thus potentially improving their function and participation. For the lower limbs, standing is usually passive (i.e., continuous, and stationary loading) but can be dynamic (i.e., simulating the forces applied during natural walking).

Previous research has demonstrated significant barriers to standing frame use, including size, accessibility, resource, and lack of knowledge about the purpose of standing frames (Goodwin et al., 2018a; Hutton & Coxon, 2011). Most young people aged 0 – 18 years in the UK who use standing frames, use them at nursery or school, rather than home (Goodwin et al., 2018a). Standing frames are used in both mainstream and specialist school settings, but more commonly in special schools. They are typically prescribed and reviewed by specialist physiotherapists, although resources usually only permit specialist physiotherapy review at approximately termly intervals (Goodwin et al., 2018a). Thus, the day-to-day management of the standing programme and practical positioning of the child in the standing frame is the role of classroom staff at school. These individuals may have a background in health, education, or care work. They may not have had extensive training with respect to moving and handling young people with CP and they require training to use standing frames.

Previous research has demonstrated significant challenges to standing frame use, including size, accessibility, resource, and lack of knowledge about the purpose of standing frames (Goodwin et al., 2018a; Hutton & Coxon, 2011); however, little is known about the 'lived' experience. Therefore, the aim of this study was to report experiences of standing frame use in education settings from the perspective of professionals and parents.

Methods

Participant identification and recruitment

Professionals were eligible to take part if they worked with young people with CP who use standing frames. Parents were eligible to participate if they had a child with CP who currently uses or has used a standing frame.

Respondents to a survey of standing frame practice (Goodwin et al., 2018a) provided their contact details if they were willing to take part in further research. From this, a shortlist of potential participants was created for each group to ensure a representative sample. These potential participants were contacted via telephone or email to explain the study, then an information sheet was emailed or posted to them if they expressed an interest. Written consent was obtained on the day of the focus groups, before discussion commenced.

The research was approved by the East Midlands - Nottingham 1 Research Ethics Committee ().

Data collection

Five focus groups were conducted in 2017 in various locations around the UK, each comprising 8-9 participants. There were three single stakeholder focus groups for each of physiotherapists, educational professionals (from a specialist school), and parents. Then, two multi-stakeholder focus groups were convened in the north and south of England respectively,

each with representation from health professionals (paediatricians, physiotherapists, orthopaedic surgeons, and occupational therapists), educational professionals, and parents.

A topic guide was developed by the research team, based on their professional and personal (JS) experience of frame use; and the results of a survey of current UK practice in using standing frames for young people with cerebral palsy (Goodwin et al., 2018a). This included: a) opinions on the results of a standing frame survey (Goodwin et al., 2018a); b) perceived benefits of standing frames; c) challenges associated with standing frame use; and d) support needs to use standing frames in school as prescribed. They were all facilitated by JG, and co-facilitated by other members of the research team (JL – multi-stakeholder focus groups, SC – physiotherapists and parents). All focus groups were audio recorded and transcribed verbatim. Participants' identifying details have been removed to preserve anonymity.

Analysis

Analysis was informed by the Framework Method (Ritchie & Spencer, 1994), which is not aligned with a particular epistemological or philosophical approach (Gale, Heath, Cameron, Rashid, & Redwood, 2013). Table 1 outlines the stages of analysis. *NVivo 11* (QSR International Pty Ltd, 2015) was used to manage the data.

- Table 1 about here -

Reflexivity and trustworthiness

All authors are current researchers in disability. AB, JC, SC, AR, JP, KM, and NK work clinically with young people with CP who use standing frames. JS is a parent of a young person with CP who uses a standing frame. Each author remained conscious of their biases to avoid influencing the analysis and write up. However, it is important to note that the authors' relevant knowledge and experience was also a strength, because it allowed for in-depth engagement with the data, including unexpected themes.

JG's coding of the transcripts and framework was discussed and clarified with the other authors as a means of quality control and rigour check. The transcripts and recordings were continuously referred to in order to ensure the analysis and interpretation was staying true to the data. Quotes from participants are provided in this manuscript as supporting evidence for the themes. A transparent audit trail in *NVivo 11* accounted for the systematic examination at each level of analysis.

Findings

The initial codes were organised into one overarching theme "*flexibility",* with four subordinate themes: (i) '*balancing education and therapy'*; (ii) '*young people's autonomy'* (iii) *'working within logistical boundaries'*; and (iv) *'competence and confidence'*.

Balancing education and therapy

Participants highlighted the difficulty in finding the right balance between education and therapy during school time:

> *Well, what's the most important thing here? Is it the standing? Is it the education? Is it this bit? Is it that bit?" … It's a very fine balancing line… constant battle between therapy and education* [Education group]

The young person's comfort was essential for their learning, but it was a constant juggling act to fit everything into the school day to facilitate this. Classroom staff in particular found themselves negotiating with young people, parents, and therapists about how and when to use the standing frame. Each of these parties had a different perspective about what the young person's priority should be, although all acknowledged that the young person's quality of life was of prime importance. Classroom staff tried to find a comfortable 'middle ground' by adjusting their approach based on their team members' advice:

We've all got the same goals. I obviously fight for the education, physio fights for the physio, but I'm very mindful that there's no point just doing 100% education in school. You need to have some therapy as well. [Education group]

Regarding the need to balance therapy and education, some participants emphasised the importance of working towards particular goals in specific environments, whilst keeping the young person's developmental stage in mind. For example, the young person's academic education and related goals may be more important in their school setting (and for their future) than standing:

Regardless of whether you're in a special school or a mainstream school you're there for a reason. Whether it's to learn life skills or to move your career forwards. And it's how we empower children and families to believe that school is about school. And developing your social skills and not just being segregated all the time and taken out of lessons to do certain things [Southern multi-stakeholder group – physiotherapist]

Despite some disagreement over the 'right' balance of education and therapy in schools, all participants believed that the benefits for the young person should be central to each decision made. They believed that holistic care from a multidisciplinary team was the best approach:

You've got to work out what are the benefits of this particular individual using this standing frame, why are we using it, and then find that right time because lessons aren't always the right time. [Education group]

Further to this, educational professionals were also mindful of the impact standing frames may have on the general classroom, this may vary between mainstream and special school settings (standing frames and wheelchairs are more common in the latter setting.) They recognised that standing frame use could not only affect the individual standing frame user, it could also disrupt others' learning:

It takes a long time. You're going to need to take them out of class or you're just going to distract everyone else. [Education group]

It was challenging to manage a classroom with a mix of seated or standing students. It required flexibility from the classroom staff (especially teachers), and affected the communication with each student in the classroom:

If you have them in a classroom with other wheelchair users as you're trying to do a lesson… where do you stand when you've got one child who is up here and all the other ones are really low down? Obviously, you want that eye contact and that face-to-face communication... Sometimes you have to change a lesson… Everything goes up in the air. [Education group]

Young people's autonomy

While it was helpful for the classroom staff to have general competence in using standing frames, it was also imperative for them to know the individual using the standing frame, their choices, and their response to standing:

If the children have got a lot of extraneous movement and they're agitated, you can end up with friction burns… Sometimes it actually depends if they've got their second skin (dynamic lycra body suit) on, if they are tired… So you have to really know your children and know what mood they're in as well.

[Education group]

At times, this required young person-specific training in collaboration with the multidisciplinary team:

It will be discussed in detail, how long they're going to be in the standing frame for, why … how they handle the child, move the child, looking for clues of where they're uncomfortable, when they're really happy, what motivates them?

[Southern multi-stakeholder focus group – mainstream school staff member]

Participants felt that standing frame use in the educational setting aimed to centre on the young person and their needs, although this was not always achieved. Classroom staff highlighted that a change in position, from standing to sitting, is important for the young people's learning:

> *From the educational point of view that is often forgotten about, is that if you find a different position, your perspective on the world and how you feel about the world and what you see and just the total sensation of your body in the world is totally different.* [Education group]

However, classroom staff had to be mindful that a change in position could be positive or negative. For example, standing could give the young people access to a new perspective in their learning, but it could also literally take away their voice:

> *I can think of one child who would just sit in the wheelchair but if they're up in the stander, they get more involved. Or then you've got some that get restricted… the frame that goes on the floor to put the VOCA (voice output communication aid) on isn't high enough because he's grown, so he can't access his VOCA during the lesson.* [Education group]

Further to this, there was a perception that the standing frame needed to be used for an activity that the young person enjoyed. A 'one size fits all' approach to the standing frame was not useful, because each young person had their own individual preferences for activities. In addition, the young person's preferences could change, which was not always taken into consideration:

> *- I think people in schools tend to assume, "Right, we've got this standing frame, we've got a tray, let's do arts and craft" … My son hates arts and craft.*
>
> *- My daughter now hates arts and crafts, I think just because she has to do it in the standing frame.*
>
> [Parent group]

The impact of standing frame use on peer interaction also varied with individuals. For some young people, standing facilitated engagement (e.g., *'when then they're standing…that eye contact is there...there's more going on socially'*), or secluded them from friends (e.g., '*they've got this ring of exclusion around them because everything is massive*.'). This was of particular importance in the mainstream setting:

> *It's fine in a special school where perhaps there are a number of children in them, but in a mainstream school, actually, it's quite isolating.* [Southern multi-stakeholder focus group – occupational therapist]

Along with the potential isolation, being different (especially in a mainstream school) could affect the young person's self-esteem:

> *It would be a confident kid who could be the only kid in the whole school who could stand up, and all the other children are sitting down doing their work at a table.* [Northern multi-stakeholder focus group – parent]

Working within logistical boundaries

Along with negotiating priorities of education versus therapy, classroom staff had to work within logistical boundaries such as time, space, staff (for moving and handling), and standing frame availability. Because of funding at some special schools, the limited standing frames were shared between many students. Although one particular specialist school tried to have a rota for standing frames, the opinion was '*it doesn't always work out*' because '*things change, don't they?'* This meant it was difficult to plan lessons in advance, as classroom staff were unsure which students would be using a standing frame at any given time:

> *You're making decisions about it all of the time and it's very, very difficult because you've got the logistics of staffing, you've got the logistics of time, you've got, "Is the standing frame available?" … So actually, it's one of the things that really, really drives our lives in school.* [Education group]

Staffing levels, rather than the prescription also determined how standing frames were used. Physiotherapists commented that the recommended standing frame use in school was three times a week, but this was based on '*what education can manage… It's their staffing level that dictates that'*. There were also situations that made standing frame use particularly difficult in the educational setting. Classroom staff from a mainstream school mentioned that they would not have the capacity for a young person to use a standing frame at their school, even though they worked with young people with CP who use standing frames in other settings:

> *We would struggle with it. Just because of the equipment that we would need to be able to use that, and because of the amount of movement that we have around the school.* [Northern multi-stakeholder group – mainstream school teacher]

Standing frame use was particularly difficult in secondary school (both specialist and mainstream) where there were a host of challenges. The young people were becoming more independent and capable of making informed choices about how and when – if at all – they used their standing frame. Also, this group could be difficult to position because of their size.

> *Some of the kids are bigger than I am and they get to the stage where they - if they've got knee flexion contractures, if it's uncomfortable and they don't want to do it, then they don't do it.* [Physiotherapist group]

Due to resource issues, some schools use shared standings frames for different young people. This added to the logistical barriers of their use due to the amount of time it took to readjust the shared standing frames for each individual. This overstretched an already busy staff:

> *If they've adjusted it and if you say you're going to get one for one of the kids, someone else might have been in and you've got to adjust every time- it just takes up loads of time.* [Education group]

Competence and confidence

In addition to the time required to adjust the standing frame for each young person, classroom staff also needed the training and skills to do it. For example, sometimes tools were needed to adjust the equipment, which was '*really, really hard'*. Most importantly, classroom staff often lacked confidence in their ability to use the standing frame, which meant that they required colleagues to help them:

> *It's also finding people who are comfortable because some students are really difficult to put in the standing frame... Like me, I'm not confident, to do any of the adjusting because I just couldn't… it just takes me forever. Whereas some people are really good at it, so I will seek them out.* [Education group]

To improve their confidence and help young people to use their standing frame comfortably, classroom staff expressed a desire to understand the 'lived' experience of using a standing frame. They felt that if they themselves knew what it was like to stand in the standing frame, they would be better able to position the young people:

> *I know it sounds daft, but you know put the leg gaiters on us and then get us in the stander and then just see… because some of them might genuinely hurt them and they can't tell us or anything.* [Education group]

Discussion

This study demonstrated the delicate balance between standing frame use, therapy and education that classroom staff must manage for young people with cerebral palsy. They juggle potential therapeutic benefits that standing frames may provide, whilst focussing on a differentiated academic curriculum, within logistical boundaries. It has previously been noted that teaching assistants are allocated such tasks without specialist health knowledge and within the busy school environment where other priorities dominate (Giangreco, Edelman, Broer, & Doyle, 2001; Lindsay, 2007; Russell, Blatchford, Bassett, Brown, & Martin, 2005).

Adding further to the difficulties of balancing priorities is that it is not always possible to separate the postural needs of their child from other health, education and social aspects (Hutton & Coxon, 2011). Although not a finding of this study, other research has noted that equipment can be recommended by therapists without careful consideration of where or how it would be used (Hemmingson & Borell, 2002). Integrating programmes into the school routine, making therapy fun, and organising therapy visits around young people's schedule (i.e. so as not to interrupt the curriculum or parts of school that young people enjoy) are essential considerations when balancing therapy and education (Hutton & Coxon, 2011). This demonstrates the need for a multidisciplinary individualised approach to standing frame use in educational settings. Indeed, educational professionals in the current study identified the way their multidisciplinary team worked toward the same goal for each young person as an area of strength.

Related to balancing priorities, participants suggested that standing frame use was generally recommended to be three times a week, which is consistent with a UK survey of standing frame use (Goodwin et al., 2018a). However, this was difficult to achieve due to logistical issues including time, space, staff (for moving and handling), and standing frame availability. This is consistent with previous research, where classroom staff identified practical solutions (e.g., more space, resources, and staff) when asked about the type of support they wanted for postural management in school (Hutton & Coxon, 2011).

Classroom staff felt that they did not always have competence and/or confidence to position young people appropriately in their standing frame. A previous study about postural management, which highlighted that teachers and teaching assistants lacked understanding regarding the purpose of different postural management strategies (Hutton & Coxon, 2011). Part of the participants' concern came from fear of causing discomfort or pain, especially in young people who were unable to communicate. This fear has been reported by classroom staff working with children with physical disabilities (Hutton & Coxon, 2011), as well as

young people with CP (Goodwin et al., 2018b). These strong emotions (e.g., fear) associated with being responsible for a young person with a disability seem to be under-recognised in classroom staff (Hutton & Coxon, 2011). Further, there may be distress associated with postural management equipment for those less familiar with specialist devices, such as teaching assistants in mainstream schools (Hutton & Coxon, 2011).

Participants in the current study, have identified this fear and lack of confidence, and emphasised the importance of knowing the individual young person's reactions to standing as a way to manage this. For example, learning about individuals' opinions on peer interaction in the standing frame was helpful. Standing frames may enhance peer interaction or segregate young people. Some young people report that using a standing frame left them isolated from their peers, whilst others did not. (Goodwin et al., 2018b).

There is a clear need for person-specific training for educational professionals to understand the individual young person, and to determine the most appropriate time and place to use a standing frame. This is in keeping with informal techniques some educational professionals already use, that is following therapists' advice, but also consulting with parents and young people themselves (Hutton & Coxon, 2011).

Limitations

Due to the qualitative nature of this study, we did not seek to generalise, nor seek cause and effect. The authors (particularly those who work with standing frame users clinically) were conscious of the need to recognise their own biases to guard against forcing the data into preconceived interpretations. However, we were similarly conscious of the importance of knowledge and experience in this field of enquiry for engaging with the unexpected through independent audits, the audit trail, and reflection through discussion and write-up at all stages.

The findings in this study may not be representative of the general population of people who work with standing frames. Participants' experiences of standing frames in the

educational setting may be influenced by a variety of factors including their training, their educational setting, the region of the UK they work in, and the population of young people they work with. However, the findings do contribute to the body of knowledge about young people with CP using standing frames in an educational setting.

Conclusions

This study highlights the complexity of standing frame use in the educational setting, including priorities regarding therapy versus education, young people's autonomy, working within logistical boundaries, and the competence and confidence of classroom staff. If a standing frame programme is prescribed to be delivered in an educational setting, strong multi-disciplinary and inter-agency communication is helpful to balance therapy versus education. Training is required to ensure the classroom staff can understand young people's individual reactions and know how to adjust the standing frame confidently. A flexible approach – inclusive of the young person's needs, logistical demands, and resource – is required.

Key Messages

- If a standing frame programme is prescribed to be delivered in an educational setting, strong multi-disciplinary and inter-agency communication is helpful to balance therapy versus education.
- Training is required to ensure staff have the skills to use the standing frame with the young person understanding their individual requirements.
- A flexible approach – inclusive of the young person's needs, logistical demands, and resource – is necessary.

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Table 1: Stages of Framework Method analysis

Stage	Description
1	Verbatim transcription.
2	Familiarisation with the recordings and transcription.
3	Open coding.
4	Developing a working analytical framework.
5	Applying the analytical framework by indexing subsequent transcripts using existing codes.
6	Charting data into the framework matrix. That is, data was summarised by category for each transcript with illustrative quotations.
7	Interpreting the data through discussion, reflection, and writing up.